

**Serving Older Persons with Visual Impairments and Their
Caregivers**

Suggestions for State Units on Aging

Promoting Systemic Development of State Family Caregiver Support Programs

National Association of State Units on Aging

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Table of Contents

	Page
Forward	i
Introduction	1
Definitions	2
Impact of Late Life Vision Loss on Older Adults	3
Impact of Late Life Vision Loss on Caregivers	4
The Older Blind Independent Living Program	6
Increasing the Aging Network's Knowledge of Vision Loss and its Impact on Older Persons	8
Developing Connections Between the Aging and Vision Services Networks	9
Coordinating the FCSP with Vision Service Programs	10
♦ <i>Outreach and Services for Older Persons with Vision Loss and Their Caregivers</i>	11
♦ <i>Educating Eye Health Professionals</i>	14
Recommendations for FCSPs	15
References	18
Older Blind Independent Living Program: State Managers List	Appendix A
National Organizations that Provide Information on Vision Loss	Appendix B
Preparing Written Materials for Persons With Visual Impairment: How to obtain Additional Information	Appendix C
Additional Reading	Appendix D

Forward

For many Americans, the loss of part or all of their vision will be a reality as they grow older. Some estimates put the number of older people who are currently experiencing some level of visual impairment at approximately 3 million. This number is expected to increase to about 6 million by the year 2030.¹ The aging network is well aware of the impending swell in the aging population, and the complex issues that will accompany this dramatic growth. The impact of vision loss on older persons and their caregivers will inevitably affect how programs and services are designed and developed and must be considered in the design and development for the future.

The purpose of this paper is to focus attention on the issue of vision loss in the older person and how this affects the relationship between the care recipient and caregiver. It offers some practical suggestions for ensuring that the National Family Caregiver Support Program (NFCSP) is developed in a way that is sensitive to the needs of older persons with vision loss and their caregivers.

While the target audience of this paper is the Aging Network, we believe Older Blind Independent Living Programs and other service providers will also find the practical suggestions and ideas presented here useful in developing and providing services for older persons with vision loss and their caregivers.

The paper first explores the impact that vision loss has on both the older consumer and the caregiver. An overview of the Older Blind Independent Living Program is provided along with suggestions for increasing the aging network's knowledge of vision loss and how to develop connections to the vision services networks. The essential role of the medical community in meeting the needs of visually impaired elders and their caregivers is also discussed. Finally, recommendations are provided in two categories-knowledge and action-to encourage states to look critically at their FCSP programs for opportunities to make them more responsive to the needs of older persons with vision loss and their caregivers.

¹ Vision Loss in an aging Society, A Multidisciplinary Perspective; John E. Crews and Frank J. Whittington, Eds. AFB Press, 2000. Page 32.

The four appendices provide: a listing of state managers of the Older Blind Independent Living Program; names and descriptions of national vision service programs; information on how to obtain help preparing written materials for persons with visual impairments; and recommendations for additional reading.

This document, as well as other publications developed under this project, may be downloaded from the NASUA web site at www.nasua.org.

Serving Older Persons With Visual Impairments and Their Caregivers

Suggestions for State Units on Aging

Introduction

Elder consumers with vision loss and their caregivers represent a distinct and often under-recognized segment of our population. Oftentimes, the opportunities to identify and address these situations are missed, not intentionally, but because the systems that are in place do not work together or do not recognize the need. Many reasons exist as to why these gaps occur. The goal of this document is to help State Units on Aging (SUA) identify, understand and address the critical issues in serving this group. Further, this document is designed to be a tool to assist States in looking critically at their programs and aiding them in addressing these concerns in the overall design and operation of their Family Caregiver Support Programs (FCSP).

The gaps that exist do so for many reasons and at various levels. First, the overall understanding of vision loss and aging and the impact it has on both the consumer and caregiver is a critical issue to consider as many misconceptions and myths exist. Second, understanding the network of vision rehabilitation services within each state is essential in helping SUAs develop programs and services that are well-integrated, thoughtful and responsive to the needs of consumers and caregivers alike. Knowing what these programs are and fostering access to them through solid partnerships and working agreements is key to obtaining the necessary services for consumers and their caregivers. Third, the examination of factors that the aging network and the vision rehabilitation and medical communities bring to the discussion along with the need for information and education of both consumers and caregivers highlights an important set of implications SUAs will need to consider when developing their FCSP. Once this is done, the SUA can assure that their FCSP is developed in a way that promotes community living and helps consumers maintain as productive a life as possible.

Definitions

Vision loss is often thought of as a normal aspect of the aging process. While it is true that advancing age may bring changes in one's vision, vision loss is not a normal part of growing older and it can range from what might be considered "normal" loss to low vision resulting from disease to being legally blind.

Normal changes in vision with age--*Presbyopia* is the most common age-related vision change in which the lens of the eye begins to lose elasticity making it harder to focus vision up close. This condition can be corrected easily with reading glasses or glasses with bifocal, trifocal or progressive, no-line lenses as well as lighting adjustments. Other normal changes in vision include declining contrast sensitivity (difficulty telling where an object ends and its background begins) and color perception (the color blue may appear darker and harder to distinguish from black). As the eye ages, the pupil gets smaller, resulting in the need for more light to see well and more time to adjust to changing levels of illumination such as going from daylight into a darkened room.²

Low vision-- refers to a level of functioning rather than a particular level of visual acuity.³ Low vision denotes a level of impairment that, even with corrective devices such as glasses, contacts, medication or surgery, makes doing everyday tasks difficult. There are treatment options for common age-related eye diseases such as *cataracts*, *glaucoma* and *macular degeneration*. However, when vision loss cannot be corrected to the normal range, vision rehabilitation services - counseling and training that can help people overcome the challenges of vision impairment - are critical for helping people to maintain independence and quality of life. The goal of vision rehabilitation is to help people with vision loss benefit from prescribed optical devices (if appropriate) to maximize the use of remaining vision, learn new ways to accomplish daily activities and take advantage of adaptive and computer technologies.

Legal Blindness-- is a term that represents an artificial distinction and has little value for rehabilitation. It is, however, significant in that it is used to determine eligibility for certain

² Eleanor E. Faye, MD and Carol J. Sussman-Skalka, CSW, MBA, "Vision Loss is Not a Normal Part of Aging". New York: Lighthouse International, 2002.

³ The Lighthouse Inc. (1996). Creative Solutions to Program Needs. *Aging and Vision Series*. Page 21.

disability benefits from the Federal Government and is the benchmark for eligibility for the **Older Blind Independent Living Program** to be discussed later⁴. Being "legally blind" refers to having vision that can be corrected to no better than 20/200 or having a visual field of 20 degrees or less in the better eye⁵. The definition of "legally blind" can vary from state to state. Few people with age-related eye disease experience total blindness.

Impact of Late-Life Vision Loss on Older Adults

Older adults who have had vision loss from an early age as the result of injury, disease or birth defect most likely have received training or have developed adaptive skills to enable them to live independently. As a result, these older adults may have a less immediate or acute need for service related to their vision loss but may need services that offer assistance based on changes in other areas of functioning. The focus of this paper is on later-life vision loss and the unique set of circumstances it brings to the caregiving situation.

Vision loss may be part of a more apparent condition facing the consumer or it may be confused with other conditions. If the consumer fails to get regular vision screening, conditions may be detected later in their progression, possibly making treatment more difficult or less successful. The lack of regular eye exams or failure of the medical community to recognize vision loss that is co-occurring with other physical problems (e.g., diabetes) are barriers to early detection and treatment

The loss of vision late in life is known to be feared more than other health conditions such as loss of mobility or limb.⁶ As a result, persons who experience vision loss are often reluctant to reveal the loss or to seek help. A number of factors help explain this. Diminishing vision in old age can evoke feelings of fear and denial and can lead older people to resist diagnosis and treatment or to seek help to cope with the vision loss they are experiencing. By acknowledging that there is a problem, seniors with vision loss may believe that they are jeopardizing their independence and placing themselves at risk for unwanted help or worse, institutionalization.

⁴ Vision Research--A National Plan: 1999-2003, National Eye Institute, National Institutes of Health, 1998.

⁵ The Lighthouse Inc. (1996) Directory of Programs & Services for Older Adults with Impaired Vision. *Aging and Vision Series*, Page 279.

⁶ The Lighthouse Inc. (1995) The Lighthouse National Survey on Vision Loss: The Experience, Attitudes and Knowledge of Middle-Aged and Older Americans, New York: The Lighthouse Inc., Page 5.

How the older person reacts to vision loss is often a critical barrier to overcome. Each person reacts to trauma and loss differently and with varying degrees of adaptability. Sometimes, consumers mask symptoms or deny that there is a problem. They may cease favorite activities such as knitting, crosswords or reading, saying that they "don't like to do it anymore". Others withdraw, decreasing opportunities to socialize because they are unable to see well enough to be able to recognize those with whom they are interacting. This withdrawal can often be mistaken for depression or some other condition and may impede the detection of vision loss.

The effect of vision loss on a consumer's mental health must also be considered. Losing one's vision late in life is often traumatic. Therefore, one must recognize the loss and allow the consumer to grieve the loss of eyesight just as she/he would grieve the loss of a spouse. This grieving process must be allowed to happen at the consumer's pace. Depression over vision loss, if unrecognized and untreated, could prevent the older person from receiving the help she/he needs.

It is vital for older adults who are suspected to have, or who have been diagnosed with vision loss, to be referred to a **low vision specialist**. A low vision specialist is an ophthalmologist or optometrist trained to evaluate not only the extent of vision loss but also to complete a "functional evaluation" of the individual with low vision. The low vision specialist may prescribe optical devices to maximize remaining vision. It may also be necessary to refer the individual for other vision rehabilitation services to learn new ways to carry out everyday tasks as well as to learn safe ways to travel independently. Only through the correct identification and measurement of the loss can the most appropriate intervention be identified and carried out.

Impact of Late-Life Vision Loss on Caregivers

Vision loss can have a dramatic impact on the caregiving dynamic. Many times, the very person who most wants to help is the one who impedes the detection, treatment and rehabilitation process. It may happen at different levels and may not be immediately apparent to either the caregiver or care recipient. The inability to recognize signs of vision

loss, the fostering of excessive dependence, resentment by both consumer and caregiver, as well as guilt, may all contribute to a dramatic change in the critical relationship that exists between caregiver and care recipient.

Simply failing to recognize signs of vision loss in loved ones can be a major factor in whether services are ever accessed or utilized. Changes in behavior such as cessation of favorite activities, isolation from social contacts, lack of eye contact and losing things at home are all potential signals of vision loss. While these behaviors can be caused by other physical conditions, the possibility of vision loss should not be ignored. Vision loss can also manifest itself through changes in how a person relates to the environment and may potentially lead to the erroneous assumption that the client has dementia. For example, a consumer experiencing vision loss may be unable to see the numbers on the thermostat well enough to adjust the room temperature correctly but the caregiver misinterprets this behavior as a sign that the consumer has dementia. Thus, care must be taken to assure correct identification of the problem and appropriate interventions. Caregivers must have access to information and materials that will help them understand vision loss, enable them to be aware of warning signs and identify appropriate interventions to help the care recipient.

Caregivers of persons with vision loss as well as professionals who work with them often assume that the care recipient is more impaired than is actually the case. Rather than allowing the consumer to re-learn tasks and maximize their remaining sight, caregivers may take over tasks the consumer might otherwise be able to do for him/herself. Over time the care recipient may become unnecessarily dependent on the caregiver or other professionals such as nurses or case managers. Thus, caregivers and professionals alike may fail to empower and support the consumer in dealing with vision loss and may actually cause the consumer to give up more independence than they need to.

In situations where over-dependence has been fostered, resentment may build in one or both individuals. Care recipients may feel that their autonomy and personal choice is being compromised or removed altogether. Caregivers may feel that they are burdened excessively or being taken advantage of. In either case, these feelings may cause erosion of

a relationship that is fundamentally different from that which existed prior to care being provided, adding stress to both parties and possibly having a negative impact on the health and/or safety of one or both persons.

Finally, caregivers may be coping with frailties of their own. Frequently, caregivers are elderly themselves and possess substantial limitations of their own. Caregivers may also be caught in a "sandwich" situation caring for both a younger child (whether the child has a disability or not) as well as an aging loved one. This can mean added stress for caregivers as they struggle to deal with their own growing limitations and add feelings of guilt and frustration for the care recipient who may feel she/he is adding to the caregiver's problems.

The Older Blind Independent Living Program

Programs designed to address the needs of persons of any age with all levels of vision loss are available in every state. However, the availability of these services varies a great deal from state to state and within local communities. Even where such services exist, older consumers and their caregivers often do not find their way into this system. Knowing what these programs are, how they fit into the broader picture of home and community based services (HCBS) and forming linkages to them is essential to addressing the needs of older persons with vision loss and their caregivers.

Vision rehabilitation and training services can be provided to older individuals with vision loss meeting the impairment criteria for admission to programs that exist in every state. A 1996 Lighthouse Inc. survey found that primarily the vision rehabilitation network provided vision services to older adults, and that only 10% of programs that participated in this survey identified themselves as service providers in the aging network.⁷ Therefore, identifying and reaching out to the vision service providers in the state is critical.

Title VII, Chapter 2 (VII-2) of the Rehabilitation Act of 1973, often referred to as the **Older Blind Independent Living Program**, authorizes formula grants to state vocational rehabilitation agencies for programs to provide independent living services for persons defined as "significantly visually impaired" who are 55 years of age or older.⁸ "Significantly

⁷ The Lighthouse Inc. (1996). Creative Solutions to Program Needs. Page 10

⁸ Rehabilitation Services Administration (2002). Title VII-Chapter 2, Annual Report for FY 2000.

visually impaired" means a reduction in vision that is at least at the threshold of "legally blind" (see definition on page 3) and that threatens the independence of the consumer. States typically set minimum impairment eligibility guidelines for their programs as a way to assure they are serving the most impaired consumers.

Since significant vision loss often interferes with normal activities of daily living (ADLs) -e.g., eating, bathing, dressing, mobility- services provided by programs funded through the Older Blind Independent Living Program are targeted to persons aged 55 or older for whom the rehabilitation of independent living skills is still feasible. The anticipated outcome of these types of services is to enable consumers to maintain their desired level of personal independence and status within the community. There is a broader outcome for society as a whole in that rehabilitation of an individual with vision loss may help reduce the burden on caregivers and delay or avoid the need for more costly long term care options.

Funding under the Older Blind Independent Living Program became available to State Rehabilitation Program offices in 1986, when approximately 25 states began receiving funding. This number has gradually increased as additions were made to the funding of this program. Today, programs are available in all 50 states, the District of Columbia, the Virgin Islands and Puerto Rico.⁹ (See Appendix A for a complete list) Funds flow from the Rehabilitation Services Administration's (RSA) budget office to State Rehabilitation Program offices in each state that operate under the umbrella of the RSA. Funding for the Older Blind Independent Living Program for FY 2001 was \$25 million. All states receive base level funding in the amount of \$225,000 per year. That amount is increased based on the total number of individuals aged 55 and older, with or without visual impairments, residing in that state.

In about half of the states, the Older Blind Independent Living Program is housed within a separate agency specializing in serving the blind and visually impaired. In the remaining states, funds are distributed to the State Rehabilitation Program office where programs for the blind and visually impaired are developed and administered, and decisions are made regarding how services for older visually impaired persons will be delivered. In some states,

⁹ The Lighthouse Inc. (1996). Creative Solutions to Program Needs. Page 56.

the Rehabilitation Program Office employs in-house personnel (teachers, therapists, low vision specialists) that provide the services directly. In other states, services are subcontracted to agencies such as local, private non-profit agencies serving the blind and Centers for Independent Living (CILs).

Increasing the Aging Network's Knowledge of Vision Loss And its Impact on Older Persons

Developing a range of services responsive to the needs of caregivers and those for whom they care depends largely on knowing enough about the issue of vision loss and the needs of older persons with vision loss and their caregivers. SUAs should actively seek to increase their knowledge of vision loss and its effect on both consumers and caregivers. Educating staff in senior centers, congregate dining and home delivered meals programs as well as adult day service programs and home service providers on the signs of vision loss is essential. Information about vision loss as well as the interventions and resources that are available need to be part of the regular training curriculum for both new and experienced staff, particularly staff of the Information and Referral/Assistance (I&R/A) programs and the Family Caregiver Support Program (FCSP). Crosstraining and continuing education opportunities that are developed jointly by both the aging and vision rehabilitation networks and presented routinely will assure both sensitivity and responsiveness to the needs of older consumers with vision loss and their caregivers.

Organizations such as Lighthouse International, The American Foundation for the Blind, the National Institute of Health's National Eye Institute, the Centers for Disease Control, as well as the state's Older Blind Independent Living Program have a wealth of information on all aspects of vision loss and its implications including: the causes and effects of eye diseases; research and survey data on vision loss and related health issues; and the best approaches for treatment and rehabilitation. These organizations are also available to provide resources and training on such topics as the causes of vision loss and its impact on functioning and the programs available in the community to assist older people with vision loss. (See appendix B for contact information on state and national organizations)

Developing Connections Between the Aging and Vision Services Networks

The aging network can play a major role in serving persons with visual impairments and their caregivers. SUAs and the Older Blind Independent Living programs should decide together which services they, as a network, will provide, which will be provided exclusively by the vision services network and which services are best provided through a joint effort.

Historically, aging service programs and vision service programs have been run independently of one another and often with each program not knowing that the other is simultaneously providing services to the same consumer. As mentioned earlier, only a small percentage of vision service programs provide services exclusively to the elderly. Therefore, it is essential that both networks talk with one another and develop a relationship that allows for cross training of staff, information sharing and mutual referral. This dialogue alone would go a long way toward resolving the knowledge gap on both sides of the equation, but it has the potential to accomplish more. By joining forces, the aging and vision service networks can identify gaps in service that need to be filled and jointly develop information sources that are comprehensive and benefit not only consumers and caregivers, but the programs themselves.

Strong collaborative relationships can enhance the range of services available to older people with vision loss and their caregivers. Forming partnerships between aging and vision service providers means not only looking at the assets each stakeholder brings to the table but also ensuring that services and efforts are not duplicated.

Collaboration also provides the opportunity to maximize and share resources. A congregate dining site in the aging network can become a meeting place for support groups for persons with vision loss or a training site for vision rehabilitation programs. Likewise, a vision rehabilitation site can be designated as an assessment site for seniors seeking assistance from the Aging Network. In Virginia for example, the SUA has worked with the Virginia Department for the Blind and Vision Impaired (VDBVI) to place Closed Circuit Televisions (CCTV) in each AAA. Older adults who are visually impaired can use these devices to read mail, pill bottle instructions, and other printed materials.

Coordinating the FCSP with Vision Services Programs

When the aging and vision rehabilitation service networks work together, both can help ensure that their interaction is helping to meet the needs of both consumers and caregivers. This can be done in a way that avoids duplication or the omission of services altogether. Consider a family system in which the consumer is receiving training and rehabilitation from the Older Blind Independent Living Program while the caregiver is receiving services from the FCSP. When staff in both networks communicate and are aware of what the other is providing, services that could maximize the efforts of each can be coordinated in a way that complements and enhances the efforts of both.

Collaborative partnerships also have the potential for a broader impact through mutual program development, joint outreach to the community and identification of consumers and caregivers who need the services of either or both networks. Vision loss may be a major precipitating factor in a consumer's need for home and community based services (HCBS) and a caregiver's need for the services of the FCSP. Collaborative partnerships can result in the establishment of information and referral systems or the development of access points that ensure that consumers with vision loss and their caregivers get the services and supports they need.

A FCSP that fosters the detection of vision loss, educates consumers and caregivers about vision loss and provides ease of movement between networks can serve as a model of collaboration to maximize services for consumers and caregivers. Such a model of collaboration will:

- **Meet the consumer and caregiver where they are** by providing a connection to vision rehabilitation services and identifying additional needs as they arise.
- **Be tailored to each caregiver and consumer situation.** Consumers with vision loss who live alone may present a different set of rehabilitation and training needs than someone living with the caregiver. Each situation needs to be evaluated based on the tasks that the person with vision loss wants to be able to do, whether or not they live

with a caregiver or live alone. The service provided to someone living alone may need to be more practical in nature (e.g., cooking skills, bathing skills) than for someone whose caregiver lives with them. In the latter situation, respite may be what is needed to relieve caregiver burden.

- **Be flexible and intermittent.** Services may need to be available on an "as needed" basis or with the flexibility to be accessed over time as needs change. For example, consumers and caregivers may need services at the onset of vision loss to deal with the changes presented at that time. Additional services may not be needed until there is a change in the condition of the older person with vision loss (e.g., health problems that affect functioning) or the caregiving situation changes (e.g., the care receiver moves to a group setting such as an Assisted Living Facility). Unfortunately, vision loss due to age-related eye disorders tends to worsen over time.
- **Encourage caregiver participation.** Actively involving caregivers and other family members has been demonstrated to be a very effective method for building confidence in both the consumer with vision loss and the caregiver. The consumer gains confidence through validation from the caregiver for their successes while the caregiver gains confidence in, and perhaps more importantly assurance that, the consumer has mastered or re-learned skills to a degree that makes him/her less dependent on the caregiver. The caregiver's involvement also validates the essential role she/he plays in the consumer's life.

1. Outreach and Services for Older Persons with Vision Loss and Their Caregivers

Because many older adults and the population in general view vision loss as a normal aspect of aging, a greater effort is needed to increase the awareness and understanding of consumers and caregivers about vision loss and options for rehabilitation and services. Vision loss is often difficult to detect or not readily apparent. Therefore, how a state conducts outreach will need to be evaluated to assure that the most effective methods are used.

For outreach to be successful, consumers and caregivers need information not only about

vision loss itself but also about the types and methods of assistance that are available. Print materials should be understandable and written at a reading level suited to the intended audience (usually 4th to 6th grade level/see Appendix C to obtain additional information). Special print styles, fonts or colors can make the text more readable. The use of alternative formats, such as Braille or audio, should also be considered. Web-sites must be easy to use and all materials should be culturally sensitive. Several national organizations can offer assistance and guidance in the development of materials for persons with vision loss (see Appendix D for a list and contact information).

In some situations, the person with vision loss may not want to acknowledge or admit the vision problem, and the caregiver may be the one making the first call for help. Therefore, caregivers must have sources of information, education and materials readily available to them to make them aware of situations that indicate the possibility of vision loss and where to find assistance.

Information on how to access the system of services for persons with vision loss is essential and may include information on which agency to call as well as specific guidelines for program participation and eligibility requirements. Equally important is education on the importance of low vision evaluations and how to contact low vision practitioners in the community. A description of what vision rehabilitation services are and the latest treatments available for various eye disorders, and pointers for asking questions should also be included.

Since it is likely that many people with vision loss may not already be receiving help, opportunities for information provision outside the traditional service network should be explored. Placing information in locations frequented by consumers and caregivers is one way to reach potential participants. Presenting information at support groups, day care and senior centers that raises the awareness of vision loss and the availability of services is another way to bring information to those who need it.

Caregivers may benefit from information and skills training on how to help their loved ones cope with vision loss while maintaining as much independence as possible. In the

1997 survey conducted by the National Eye Institute (NEI), caregivers of persons with vision loss indicated that having information on household safety, the latest treatment options, support groups and how to foster emotional support and self-esteem are useful tools.¹⁰ SUAs can use the development of the FCSP to look at whether they coordinate these services with the vision rehabilitation network or develop new materials and programs targeted specifically to consumers with vision loss and their caregivers.

Some older adults with vision loss have found that peer counseling and peer support groups are among the most valuable services for helping them to cope with vision loss. The social interaction and sharing of experiences and solutions can have a positive impact on the self-esteem for those who attend such programs. Often, family members and caregivers are encouraged to participate in these groups, or in separate family/caregiver support groups thus affording them a better understanding of the challenges facing their loved ones.

The "supplemental services" category of the NFCSP may be used to pay the costs of assistive technology, adaptive equipment, and home modifications for caregivers when the consumer has a visual impairment. For example, using FCSP funds to purchase all or part of an assistive device, such as a closed circuit television (CCTV) for reading, could enable the consumer to read and pay bills independently, thus relieving some of the burden placed on the caregiver. It is important for FCSPs to become familiar with the types and uses of the various assistive technologies that are available to help consumers who have vision loss¹¹. While this may already be happening in many areas, FCSP funds could be put to greater use by augmenting and strengthening programs already in place.

Partnering of the FCSP with the vision rehabilitation network to develop counseling, support groups and caregiver training when the care recipient has vision loss has the potential to broaden the services of both networks. Counseling can involve traditional therapeutic approaches, family treatment, or individual problem solving. Support groups can be focused around providing specific information on eye diseases, the impact of vision loss on independent living, and resources and services in the community for the consumer

¹⁰ The National Eye Institute (1997) *Life With Low Vision, A Report on Qualitative Research Among People with Low Vision and their Caregivers*. Conducted by Prospect Associates. Page 5.

¹¹ The Lighthouse Inc.'s 2001 publication entitled: *Introduction to Adaptive Computer Technology*, provides an overview of adaptive devices including ordering information and additional resources. Information on how to obtain this publication can be found in Appendix D.

with vision loss.¹² Education and training can involve teaching adaptive living skills and use of adaptive equipment for the consumer and techniques for coping that the caregiver may use to help them deal with everyday issues. Education and training of the caregiver can also function as a follow-up to the training provided by the Older Blind Independent Living program to both enhance and reinforce what was learned.

2. Educating Eye Health Professionals About the FCSP And Vision Service Programs for Older Persons

The medical community is a critical partner in the overall effort to assure that the needs of older persons with vision loss and their caregivers receive the evaluation and assistance they need. Physicians' offices can be important access points to the system. Medical doctors and eye health professionals and staff who work in their offices must be made aware of programs and services for persons with visual impairments and how to access them.

Eye doctors and low vision specialists typically operate independently of one another. A regular eye exam by an ophthalmologist or optometrist is essential for detecting eye diseases and other conditions that can lead to vision loss. If a person does have vision loss, a referral to a low vision specialist who can perform a specialized low vision evaluation should be made so that the individual's vision can be evaluated and if appropriate, optical devices prescribed to maximize existing vision. Therefore, it is essential for the diagnosing ophthalmologist or optometrist, if not a low vision specialist him/herself, to make a referral for further evaluation and follow up.

Eye health professionals need to be informed about vision rehabilitation services and how to access them. They also need to know about the FCSP and the supports available for caregivers that may be stressed and overburdened in caring for an older person with vision loss. SUAs and vision rehabilitation service agencies must put their collaborative relationships to work to reach out to the medical community to inform them of their networks, the programs and services that are provided and how to make a referral for evaluation and services. Inviting eye health professionals to share in the development and distribution of materials related to eye diseases, vision loss, and the methods for detection

¹² The Lighthouse Inc.'s 2002 publication entitled: *Programs for Partners of People with Impaired Vision: A Discussion Guide for Support Group Leaders* by Carol J. Sussman-Skalka, CSW, MBA and Verena R. Cimarolli, Ph.D., is a useful tool for staff wanting to start a support

and treatment would mutually benefit all the stakeholders. Inviting ophthalmologists and optometrists to participate in caregiver and staff training would also be useful.

A 1997 National Eye Institute study revealed that many caregivers believed that counseling from eye care professionals would make a difference in how those they cared for coped with vision loss.¹³ Therefore, both SUAs and the vision service network must strive to involve eye care professionals in the development of their education programs, support groups and training.

Recommendations for FCSPs

Meeting the needs of older persons with visual impairments and their caregivers is a multi-faceted task involving many players with diverse and dynamic roles. SUAs can play a critical role in assuring that the FCSPs they develop involve all the players and are truly responsive to the needs of consumers and their caregivers. This takes understanding, creativity and flexibility along with a goal to build collaborative relationships in the community. To begin, SUAs must consider the elements that need to be considered in their own programs and how well they are equipped to meet the needs of consumers with vision loss and their caregivers. The elements fall into two major categories: **knowledge** and **action**.

- ❖ In order to address the needs of caregivers when the consumer has vision loss, the FCSP needs to **know**:
 - ◆ The scope of existing vision rehabilitation programs and services within the state and at local levels, the service gaps that exist, and the opportunities to enhance what is already available.
 - ◆ If their services have been designed to be easily accessible to older persons with vision loss and their caregivers.
 - ◆ The inter-relationship of the multiple health concerns exhibited by older persons and how vision loss may compound this phenomenon.

group. Information on how to obtain this publication can be found in Appendix D.

¹³ The National Eye Institute (1997) *Life With Low Vision, A Report on Qualitative Research Among People with Low Vision and their Caregivers*. Conducted by Prospect Associates. Page 51.

- ◆ The amount of information available to older consumers and caregivers about vision loss and the services that are available to meet the needs of persons with vision loss.
 - ◆ The knowledge gaps of both the aging and vision rehabilitation networks with respect to vision loss and its effects on caregivers and how to best address them.
 - ◆ The medical community's (and particularly eye health professionals) knowledge of programs and services available from the aging and vision rehabilitation networks.
- ❖ In order to adequately address the needs of caregivers when the consumer has vision loss the FCSP needs to take **action** to:
- ◆ Engage in a dialogue with Older Blind Independent Living Programs to build collaboration and identify connection points that allow for easy access to and movement between both networks.
 - ◆ Form partnerships with Older Blind Independent Living Programs, Public Health Programs and other providers of HCBS to develop holistic approaches to addressing the multifaceted needs of the older consumer with vision loss and their caregiver.
 - ◆ Evaluate the range of services available from both networks and look for gaps and opportunities to enhance what is provided.
 - ◆ Assess aging programs to assure that they are responsive to the needs of older people with vision loss and their caregivers.
 - ◆ Assure that both the aging network and vision rehabilitation networks educate each other on respective programs and roles.
 - ◆ Promote the important role the caregiver can play in fostering consumer direction in not only aging programs but also in vision and other rehabilitation programs.

- ◆ Join with the vision rehabilitation services programs to educate the medical community about the rehabilitation potential of older persons with vision loss and the services provided by the vision services programs and the FCSP in their communities.
- ◆ Develop materials and make available information to caregivers about vision loss and the options available for rehabilitation and service.

Because vision loss affects many areas and can have dramatic and often debilitating consequences, great care must be given to outreach and the identification of the needs of these elders. Staff in both the aging and vision rehabilitation networks must be knowledgeable and aware of partnerships between their respective networks. Eye health professionals must be considered key players at all stages and involved more fully in detection, referral and service provision. No one network alone can adequately meet the needs of this special group. Together, the Aging Network, the Vision Rehabilitation Network and the medical community can ensure support to the caregiver and appropriate interventions to enable the older person with vision loss to remain as independent as possible.

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Appendix B

National Organizations That Provide Information

On Vision Loss in Older Persons

American Council of the Blind

The American Council of the Blind is the nation's leading membership organization of blind and visually impaired people. The Council strives to improve the well-being of all blind and visually impaired people by: serving as a representative national organization of blind people; elevating the social, economic and cultural levels of blind people; improving educational and rehabilitation facilities and opportunities; cooperating with the public and private institutions and organizations concerned with blind services; encouraging and assisting all blind persons to develop their abilities and conducting a public education program to promote greater understanding of blindness and the capabilities of blind people.

1155 15th Street, NW, #720

Washington, DC 20005

Tel: (202) 467-5081

www.acb.org

American Foundation for the Blind

The American Foundation for the Blind is dedicated to addressing the critical issues of literacy, independent living, employment, and access through technology for Americans who are blind or visually impaired.

11 Penn Plaza, Suite 300

New York, NY 10001

Tel: (800) 232-5463

www.afb.org

Lighthouse International

Lighthouse International is a leading resource worldwide on vision impairment and vision rehabilitation. Through its work in vision rehabilitation services, education, research, prevention and advocacy, Lighthouse International enables people of all ages who are blind or partially sighted to lead independent and productive lives.

111 East 59th Street

New York, NY 10022-1202

Toll free: Information and Resource Service: 800-829-0500; info@lighthouse.org

Tel: 212-821-9200

Fax: 212-821-9705

TTY: 212-821-9713

www.lighthouse.org

www.lighthouselink.org (Fall 202)

National Eye Institute, National Institutes of Health

Established by Congress in 1968 to protect and prolong the vision of the American people, the National Eye Institute (NEI) conducts and supports research that helps prevent and treat eye diseases and other disorders of vision. Additionally, through the National Eye Health Education Program (NEHEP), NEI has developed public and professional education programs that help prevent blindness, reduce visual impairment, and increase awareness of services and devices that are available for people with low vision.

National Eye Institute

National Eye Health Education Program (NEHEP)

Building 31, Room 6A32

31 Center Drive MSC 2510

Bethesda, MD 20892-2510

Tel: (301) 496-4248

www.nei.nih.gov

National Federation of the Blind

The National Federation of the Blind (NFB) is the nation's largest and most influential membership organization for blind persons. The NFB provides a wide variety of services to visually impaired people including publications in large print, Braille, and audiocassette, and a catalogue of aids and appliances.

1800 Johnson Street

Baltimore, MD 21230

Tel: (410) 659-9314

www.nfb.org

Independent Living Services for Older Persons Who Are Blind

This program, found in every state, is funded through Title VII, Chapter 2 of the Rehabilitation Act. The program provides training in skills of routing daily living, travel, communication, provision of adaptive devices, low vision services, family and peer counseling, and community integration such as outreach and information and referral.

U.S. Department of Education

OSERS/RSA

400 Maryland Avenue, SW

MES Building, Room #3327

Washington, DC 20202-2741

Tel: (202) 205-9320

Fax: (202) 260-0723

www.ed.gov/offices/OSERS/RSA/Programs

Appendix C

Suggestions for Preparing Written Materials for Persons With Visual Impairments

Lighthouse International has published two booklets that should prove useful to anyone developing materials that will be used by individuals with visual impairments. They are entitled: ***"Making Text Legible: Designing for People with Partial Sight"*** and ***"Effective Color Contrast: Designing for People with Partial Sight and Color Deficiencies"***. Both texts are authored by Aries Arditi, Ph.D.

In ***"Making Text Legible..."*** basic guidelines are provided that will aid in developing printed materials that are readable by nearly everyone.

In ***"Effective Color Contrast..."*** the guidelines for making effective color choices in printed materials are discussed. The author explains the perceptual attributes of color's hue, lightness, and saturation and how these affect a document's legibility.

These publications may be downloaded from the Lighthouse International web site at: www.lighthouse.org. To obtain printed copies of these publications contact: Lighthouse International, 111 East 59th Street, New York, NY, 10022-1202, Tel: (800) 829-0500; Fax: (212) 821-9784; TTY (212) 821-9713, or email: info@lighthouse.org.

Appendix D

Additional Reading

When Your Partner Becomes Visually Impaired: Helpful Insights and Tips for Coping by Carol J. Sussman-Skalka, CSW, MBA.

This booklet provides supports and information to aid the spouses and partners of persons with visual impairments. Some of the concerns that are discussed include: understanding what your partner can see and do, communicating successfully, relating to family and friends, dealing with independence and dependence issues, realizing the benefits of vision rehabilitation and handling stress.

Programs for Partners of People with Impaired Vision: A discussion Guide for Support Group Leaders by Carol J. Sussman-Skalka, CSW, MBA, and Verena R. Cimarolli, Ph.D.

Directed to peer and professional group leaders interested in developing support group programs to help sighted partners address their feelings and issues, this discussion guide outlines an eight-session program that can be adapted easily to meet the specific needs of participants.

Vision Loss is Not a Normal Part of Aging - Open Your Eyes to the Facts! By Eleanor E. Faye, MD, FACS and Carol J. Sussman-Skalka, CSW, MBA.

This booklet provides information on what changes to expect in vision as we age, tips for keeping eyes healthy, and the four most common causes of age-related vision loss. It also includes a discussion of treatment options, vision rehabilitation services and the benefits of involving family and friends.

Family and Friends Can Make a Difference - How to Help When Someone Close to You is Visually Impaired by Carol J. Sussman-Skalka, CSW, MBA

Targeted to relatives and friends of persons with vision loss, this booklet seeks to help them understand vision loss and the emotional impact it can have on an individual. The booklet also describes vision rehabilitation services and provides guidance on making the most of existing vision, orientation and mobility training, relearning tasks of daily living, coping with vision loss and learning from others.

Aging and Vision.

This five-volume series published by The Lighthouse, Inc. offers extensive information on working with older adults with impaired vision. ***Aging and Vision*** is the culmination of a project conducted by The Lighthouse, Inc., with the support of the National Institute on Disability and Rehabilitation Research (NIDRR) and the U.S. Department of Education. The project identified three objectives: 1) to locate services, 2) to identify effective service components and models and 3) to create and evaluate a multidisciplinary curriculum on vision rehabilitation. The five volumes in the series are:

- ***The Directory of Programs and Services for Older People with Impaired Vision***
- ***Critical Concerns and Effective Practices: Final Focus Group report***
- ***Creative Solutions to Program Needs***
- ***The VisualEyes Curriculum***
- ***Workbook***

Family Involvement: Maximizing Rehabilitation Outcomes for Older Adults with a Disability by Cynthia Stuen, DSW.

This guidebook offers strategies that have been developed and refined over time to involve the older adult with impaired vision and the family in a positive rehabilitation process that includes helping families deal with the pain, guilt, fear and resentment associated with vision loss. The guide contains guidelines for staff preparation and training, as well as assessment guidelines and practical strategies for adopting a family-oriented model.

Introduction to Adaptive Computer Technology

This publication offers consumers guidance on the purchase of an adaptive device. It includes an overview of available adaptive devices, costs and information on manufacturers.

For more information, or to order these publications, please contact:

Lighthouse International

111 East 59th Street

New York, NY 10022-1202

Email: info@lighthouse.org

Web: www.lighthouse.org

www.lighthouselink.org (Fall 2002)

Phone: 800-829-0500

Fax: 212-821-9784